DOCUMENT RESUME

ED 246 572 EC 162 760

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TITLE Increasing the Effectiveness of Parents of Handicapped Children: Selected Resources.
PUB DATE [84]
NOTE 14p.
PUB TYPE Guides - Non-Classroom Use (055) -- Reference Materials - Bibliographies (131)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Coping; *Disabilities; Elementary Secondary Education; *Emotional Adjustment; *Family Problems; Family Relationship; Parent Attitudes; *Parent Participation; Parent Teacher Cooperation

ABSTRACT

The paper reviews the effects of a handicapped child upon parents and families in terms of adjustment responses, stress, behavior and role change, divorce, economic functions, and general coping and support systems. Professionals desiring to enhance parent involvement must first be sensitive to the parent's emotional well-being and must be able to help parents deal with critical incidents involved in the child's care. The importance of empathy and trust is emphasized, as is the ability to convey clear and accurate information and referrals to appropriate resources. The paper concludes with an annotated bibliography listing 20 books and manuals describing approaches for working with parents. (CL)

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INCREASING THE EFFECTIVENESS OF PARENTS OF HANDICAPPED CHILDREN: SELECTED RESOURCES

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EC162760

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Professionals, as Counselors, Psychologists, Educators, and Support Personnel, all play important roles in improving the quality of life for a child with a handicap. However, the people with the longest term, constant, and most intense relationship with handicapped children are their parents. Professional must be aware of how to help parents of handicapped children.

The importance of parental involvement in all aspects of the educational planning and placement process for handicapped children has been confirmed and reconfirmed. Yet excellent intervention programs may never realize their potential due to the collaspe of a concerned but overwhelmed family. While a child's handicap does not necessarily preclude the pleasures of parenthood, the satisfaction that may be realized by accomplishments of the child may be overlooked and overshadowed by the frustrations the parent experience. Professionals assuming helping roles with parents of handicapped children must become aware of what it means to have a child who is handicapped in the family; the effectiveness of providing supportive assistance to families during such life crises; and strategies, techniques or models for providing aid.

Few parents have been trained or prepared to deal with the situations and problems involved in parenting a handicapped child. A review of the literature on parents with a handicapped child reveals several common adjustment responses. Kubler-Ross (1969) researched the reactions of families to the loss/death of a family member, and observed five stages: denial, anger, bargaining, depression, and acceptance. Similiar parental responses were reported by Livneh and Evans (1984) while observing the phases of adjustment to physical disability. These researchers described

the following reactions: shock, anxiety, bargaining, denial, mourning, internalized anger, externalized aggression, acknowledgement, acceptance and adjustment.

Not every parent will go through all the stages described or go through the stages in the same manner or in the same sequence. However, it is important to realize that a parent maybe in any one or none of these stages when they are requested by professionals to become involved in the educational planning and placement process on behalf of their handicapped child. Furthermore, there are many incidents and crises during the development of any handicapped child that can reopen fears and feelings of denial, anger, depression or other signs of stress.

Researchers have well established that the presence of a handicapped child in the family may be the source of much stress. However, in the application of research findings, professionals are often not sensitive enough to the amount and extent of stress which the presence of a handicapped child may contribute to the dynamics of the family. Price-Bonham and Addison (1978) reviewed the literature on family stress related to having a handicapped child. These researchers reported increased divorce and suicide rates among parents of retarded children.

Gallagher, Cross and Scharfman (1980) explored the influence of the father in caring for the handicapped child. Measures of parental stress, social supports, parental-role functions, and satisfaction were obtained from 50 pairs of parents. Results indicated that 48% of fathers and 58% of mothers did not report measurable stress despite the presence of a handicapped child in the family. However, many families did experience mild to major stress (i.e., 58%of fathers and 42%of mothers). Several

changes in behavior were noted by parents which resulted from having a handicapped child. Included in these parental behaviors were changes in sleeping habits, vacations, social activities, recreation, as well as sex difficulties.

Wikler (1983) examined periodic stresses in families with a handicapped child. Results indicated higher levels of stress were experienced by transition families (i.e., with an adolescent and/or adult handicapped child) as compared to non-transition families with a handicapped child in other age groups. Several types of stressor events were significantly higher for transition families. These events included excess time demands on the mother, limits on family opportunity, dependency needs of the child, lack of activities for the child, poor health of the mother, low family integration, and behavior problems of the child.

Roesel and Lawlis (1983) examined the relationship of divorce rate to a diagnosis of genetic disability/mental retardation. The adaptive response of the families of such children would then be measured by their divorce rate. The sample consisted of families from genetic screening and counseling services, and families from a state residential facility for the mentally retarded. Results indicated that when the divorce rate for the 2 groups were combined, there were no significant differences. However, results suggested that for young parents, the birth of a first born male handicapped child was significantly related to risk for divorce.

The birth of a handicapped child may affect a family's economic, physical and psychological functions. Financially, there is often great expenses involved in the care and education of a handicapped child.

Adapted equipment, medical care--which may or may not be covered by health insurance, pleasurable toys which may be purchased to help compensate for a child's passive exploration of the environment, therapies, transportation to appropriate services, etc. may each be required to support the child's optimal development. Additionally, the physical and psychological strain on family members, related to the presence of a handicapped child in the family may also be tremendous.

Professionals must provide parents with assistance in developing and/or enhancing support systems which will improve their ability to cope, enhance family relationships, and provide the means to obtain concrete skills in advocacy, resource information, and peer supports. After diagnosis of the handicapping condition, when feelings have been addressed, many parents make an emotional accommodation so that they can move forward as parents. However, parents may continue to struggle with distressing feelings for many years. These feelings may block appropriate parental behaviors. The actions of professionals can give support, reality based information, and hope to parents.

Professionals must have a working knowledge of techniques and strategies that will assist parents, with a handicapped child, cope and adapt to critical incidents involved in the care of the child. Consequently, certain essential characteristics must be exhibited by professionals working with parents of handicapped children. These characteristics include the ability to provide emotional support, provide clear and accurate information, enlist the help of other parents, and provide adequate training programs for parents (Karnes and Teska, 1980).

Professionals must assess the parent's reaction to the child's handicap, and the level of need indicated through the family system. Professionals must get to know each parent as completely as possible in order to provide supportive assistance geared to the needs of each family. Most importantly, professionals must develop an empathetic approach to working with parents of handicapped children. Such an attitude would permit professionals to assist parents in recognizing the birth of the child as an element in the continuum of adult life experiences.

Professionals must clarify what is confidential, in the information shared through the helping relationship, in order to build trust. Additionally, professionals must develop active listening skills; must gather information that will assist in understanding the functioning level of the family unit; and must address the informational needs of the family using understandable terminology. These strategies and techniques would enable professionals to provide supportive assistance to connect families with resources and materials that provide maximum benefits to the handicapped child and his/her family. Such preventive intervention methods represent approaches that help the family of a handicapped child develop a proactive stance as opposed to merely reacting to stress.

Currently, there is a growing trend toward keeping a handicapped child within the family unit. This trend creates a need to help families with a handicapped child adapt to problems which may become manifest. Professionals must help parents see how interesting and unique their handicapped child may be. In order to encourage parent involvement and to support and enhance the family's role in the child's development, professionals must communicate that they value family members as people and their development and accomplishments as goals worth striving for.

There are many books and several programs that are excellent models for professionals to use in designing their own intervention program for parents of handicapped children. By recognizing the needs of such families, counselors, teachers and other professionals can broaden their role and serve a needed function, namely, increasing the effectiveness of parents of handicapped children. This article concludes with an annotated listing of selected books, and training programs, that describe approaches to working with parents.

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Kubler-Ross, E. On Death and Dying. New York: Macmillan, 1969.

Livneh, H. and Evans, J. Adjusting to Disability: Behavioral Correlates and Intervention Strategies. The Personnel and Guidance Journal. (February 1984), 363-365.

Price-Bonham, S. and Addison, S. Families and Mentally Retarded Children: Emphasis on the Father. The Family Coordinator. 3(1978), 221-230.

Roesel, R. and Lawlis, G. Divorce in Families of Genetically Handicapped/ Mentally Retarded Individuals. The American Journal of Family Therapy. 11(1983), 45-51.

Wikler, L. Periodic Stresses in Families of Children with Mental Retardation. Unpub. paper presented to American Association on Mental Deficiency. Annual Convention, Dallas, Texas, 1983.

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Berger, E. Parents As Partners in Education: The School and Home Working Together. St. Louis, Missouri: The C.V. Mosby Co., 1981.

Written to help school personnel and parents work together more effectively. Includes strategies that will help teachers, paraprofessionals, community workers in children's services, and professionals who implement programs of parent involvement. Concludes with a bibliographic listing of resource materials, films, books, and pamphlets.

Chinn, P., Winn, J., and Walters, R. Two-Way Talking With Parents of Special Children: A Process of Positive Communication. St. Louis, Missouri: The C.V. Mosby Co., 1978.

This book deals with how to develop more effective communication patterns in the socialization process of a "special child." Particular focus is given to communication in the triad of relationships existing among family, child, and school; and how it can be used more effectively to facilitate those interactions. The book concludes with an annotated list of agencies and organizations that assist parents and professionals.

Deppe, P. and Sherman, J. The High Risk Child: A Guide for Concerned Parents. New York: Macmillan Publishing Co., Inc., 1981.

Designed to help parents deal in the best possible manner with the problems of children with handicaps. Discusses the factors that may contribute to the birth of a high risk child; care of the child before birth, and genetic counseling; recording family and prenatal history; recording developmental milestones; assessment issues; coping with the problems of caring for a handicapped child; the educational system; and concludes with advice from parents with such a child. Includes a resource guide for parents, a listing of associations, glossary of terms, and a bibliography.

Dickerson, M. Fostering Children with Mental Retardation. Ypsilanti, Michigan: Institute for the Study of Children and Families, Eastern Michigan University, 1977.

A manual used in training families who provide services to foster children with developmental disabilities. The manual is divided into two parts. The first part describes principles of positive parenting, the second part is designed to assist in assessing children and planning ways in which they can facilitate children's growth and development.

Dickerson, M. and Eastman, M. Training for Parents of Children with Developmental Disabilities. Wayne, Michigan: Wayne County Intermediate School District, 1982.

A manual to be used by professionals to train parents who have a developmentally disabled child residing at home and receiving services

from the public school. The materials is presented in two manual: Parent's Manual and Instructor's Manual. The Parent's Manual is designed to gradually introduce parents to terminology uniquely functional in the discussion of the problems around developmental disabilities. The Instructor's Manual is designed as a guide in the training of parents of children with developmental disabilities.

Dinkmeyer, D. and McKay, G. Systematic Training for Effective Parenting. Circle Pines, Minnesota: American Guidance Service, Inc., 1976.

Provides suggested techniques and strategies to assist parents in developing more effective ways to relate to their child. Includes cassette tape illustrations of typical parent-child situations, discussion guide cards, posters, charts of the program's major concepts and principles, a leader's manual, as well as a parent handbook.

Earhart. E. and Sporakowski, M., Ed. Special Issue: The Family with Handicapped Members. Minneapolis, Minnesota: National Council on Family Relations, January 1984.

The focus of this special issue is on families with a handicapped member. The importance of viewing the family as a system; responses of families to having a handicapped member; decisions about in-home or out-of-home placement; effects of a family subsidy program for young handicapped children; issues related to parental involvement; and recommendations for policy are presented in the article.

Featherstone, H. A Difference in the Family: Life with a Disabled Child. New York: Basic Books, Inc., Pub., 1980.

Focuses on the family of a handicapped child. Discusses the fear, the anger, the guilt, marital stress, and the effects on the sibling of a handicapped child. Describes the parent-professional relationship from the perspective of getting and giving help, and concludes with the issue of acceptance of the handicap.

Gallagher, J., Ed. Parents and Families of Handicapped Children. San Francisco, California: Jossey-Bass Inc., 1980.

Discusses the interaction between the handicapped child and the family system of which he or she is a part. Chapters address the special problems of parental expectation and what failure to meet those expectations means for the adaptation of the handicapped child; attempts to intervene to help the child and the family; and parent involvement programs.

Jones, R., Ed. Reflections on Growing Up Disabled. Reston, Virginia: The Council for Exceptional Children, 1983.

Provides a first hand account of the experiences and perceptions of disabled persons themselves, as well as the views of parents of disabled children. The book covers the periods of childhood, adolescence, and adulthood. Contains a bibliography of documents in the Educational Resources Information Center (ERIC) and Exceptional Child Education Resources data bases.

Knudstrup, K. and Zimmermann, R. Parent Awareness Program. University Center, Michigan: Delta College, 1983.

Describes a "Parent Awareness Program" designed to assist parents in becoming "More effective persons in managing their lives and dealing with the problems associated with raising a developmentally disabled child." Provides a discussion of mental retardation, cerebral palsy, epilepsy, autism, and learning disabilities. Contains a glossary for developmental disabilities which includes definitions of commonly used general special education terms, professional jargon and cryptic statements, frequently used abbreviations, categorical areas of impairment and definitions, some journals available to parents, a bibliography of books, and a list of clinical abbreviations. Also included are handouts which can be used in conjunction with the training program.

Lillie, D., Trohanis, P., and Goin, K. Teaching Parents to Teach: A Guide for Working with the Special Child. New York: Walker and Co., 1976.

This book offers a framework for planning, organizing and implementing parent involvement activities in early childhood programs. Describes the scope and operation of parent involvement programs, and concludes with an annotated bibilography of resources for parent programs.

Marion, R. Educators, Parents and Exceptional Children. Rockville, Maryland: Aspen Systems Co., 1981.

This book describes roles that teachers can adopt to fulfill meaningful functions while seeking to involve parents of exceptional children and youth in special education. Chapters describe the effects of the exceptional child in the family; roles for helping teachers in special education; and involving parents of mentally retarded, learning disabled, multihandicapped, behavioral disordered, and abused exceptional children. The book concludes with a discussion of involving parents of exceptional children in transcultural settings.

Morrison, G. Parent Involvement in the Home, School, and Community. Columbus, Ohio: Charles E. Merrill Pub. Co., 1978.

Intended for parents, paraprofessionals, professionals and students. Provides suggestions for designing strategies and means for parents to become active in education endeavors. Provides a rationale for parent

involvement programs, discusses ways in which parents can become involved in early childhood settings other than the home, and explores the problems which confront parents of the handicapped.

Paul, J., Ed. Understanding and Working with Parents of Children with Special Needs. New York: Holt, Rinehart and Winston, 1981.

Provides basic information and suggestions that will be helpful to teachers and parents in their cooperative educational planning and programming for handicapped children. The book focuses on the special education of young children with moderate or severe handicaps. It concludes with an historical view of exceptionality, parent's roles, parent organizations, services for parents, economic support, and service delivery systems.

Pearlman, L. and Scott, K. Raising the Handicapped Child. Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1981.

Provides practical information to families regarding children's rights and opportunities. Describes what should be available in the way of education, vocational training, financial aid, medical treatment, and social organizations.

Seligman, M. Strategies for Helping Parents of Exceptional Children. New York: The Free Press, 1979.

Written to aid teachers in working more effectively with parents of handicapped children. Discusses the rationale for parent involvement; factors contributing to positive and negative teacher and parent relationships; realities of family life with a handicapped child; critical incidents encountered by teachers; and concludes with an annotated listing of resources to help teachers help parents.

Stewart, J. Counseling Parents of Exceptional Children. Columbus, Ohio: Charles E. Merrill Pub. Co., 1978.

The thrust of the book is to provide suggestions and information that assist in improving the ability of practitioners to relate to parents of handicapped children in productive and meaningful ways. Discusses the counseling relationship; counseling parents of handicapped children by level of severity; and concludes with principles of helping parents of gifted children.

VanPelt, J. A Peer Support and Personal Growth Group for Parents with a Child who is Developmentally Disabled or Delayed. Virginia Beach, Virginia: Virginia Beach Mental Retardation/Developmental Disabilities Program, 1981. ED 209 846.

Describes the development of a personal growth and peer support group for parents of developmentally delayed or disabled children. The program was designed to help parents adjust expectations about their infant or young child and to accommodate the handicap.

Activites to be used in conducting the group are included.

Webster, E. Counseling with Parents of Handicapped Children: Guidelines for Improving Communication. New York: Grune & Stratton, 1977.

This book attempts to bridge the gap between education and psychotherapeutically oriented counseling with parents of handicapped children. It describes giving and receiving information, establishing a basic contract of understanding between counselor and parent, and discusses the mechanics of both beginning and terminating a series of sessions.